

MEMORANDUM

DATE: July 13, 2007

TO: Joseph B. Keyes, Ph.D., DMMA
Policy and Program Development Unit

FROM: Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

RE: 11 DE Reg. 18 [DDDS Proposed Eligibility Regulation]

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Health and Social Services/Division of Developmental Disabilities Services' (DDDS) proposal to amend its eligibility criteria for DDDS services published as 11 DE Reg. 18 in the July 1, 2007 issue of the Register of Regulations. As background, in April 2007, DDDS shared a pre-publication draft of new eligibility standards with the SCPD, Developmental Disabilities Council (DDC), and the Disabilities Law Program. (DLP). DLP submitted the attached April 25 critique to DDDS. This was followed by an April 26 meeting with DDDS Administration in which representatives from the SCPD, DDC, Governor's Advisory Council for Exceptional Citizens (GACEC), and DLP participated. All the aforementioned councils were consistent in endorsing the DLP's comments. The formally published new eligibility regulations contain few changes from the pre-publication draft. SCPD has the following observations.

First, DDDS requires submission of all written comments by July 25, 2007. This violates the Administrative Procedures Act (APA), Title 29 Del.C. §10118(a). As a matter of law, individuals have the right to submit written comments for thirty (30) days after publication. The notice is affirmatively misleading. As a result, the Division should republish the proposed regulation with a notice which complies with the APA.

Second, the only substantive change prompted by the DLP's previous commentary is the addition of §1.5 which clarifies that the onset of the qualifying disability is before age 22, not age 18. However, for simplicity, the Division may wish to consider deletion of §1.5 and incorporating the concept in §1.3. Section 1.3 would then read as follows:

1.3. a disability/disorder originating before age 22 attributed to one or more of the following:

Third, §1.0 in the bound version of the Registry is obviously missing some words. It is also inconsistent with §1.3 which refers to both “disability/disorder” while §1.0 only refers to “disability”. Section 1.0 could be corrected by substituting the following:

1.0. The Division of Developmental Disabilities Services provides services to individuals with a developmental disability/disorder who meet all of the following criteria:

Fourth, the format of the regulation is extremely “sloppy”. For example, there is no punctuation whatsoever at the end of §§1.1, 1.2, 1.3.4, 1.4.1.2, and 1.5. It resembles a conceptual draft rather than a formal regulation.

Fifth, SCPD understands that DDDS is considering “grandfather” language. However, as currently written, it is likely that some current DDDS clients would not qualify under the 2007 proposed regulation. For example, if someone originally qualified “with a neurological condition closely related to mental retardation”, they may literally not meet the 2007 draft standards. Alternatively, the current regulation only requires that individuals with Prader Willi or brain injury have “substantial functional limitations in 2 or more ...adaptive skill areas” while the 2007 draft imposes a more prescriptive standard, i.e., “significant limitation in adaptive behavior ...that is at least two standard deviations below the mean” on standardized measures. When this was addressed at the April 26 meeting, DDDS Administration confirmed that it does not intend to reassess eligibility of current clients. Rather, their eligibility would essentially be “grandfathered”. However, DDDS has declined to clarify this in the regulation. Consistent with the April 25 commentary, DDDS could accomplish this in different ways.

One option would be to change the introduction as follows:

The Division of Developmental Disabilities Services (DDDS) provides services to individuals with a developmental disability/disorder who were determined eligible under a prior eligibility regulation or, for individuals applying after the effective date of this regulation, who meet the following criteria:

A second option would be to add a sentence or a regulatory note at the end akin to the following:

DDDS clients determined eligible under a previous regulation shall not be required to requalify for eligibility, i.e., their eligibility is “grandfathered”.

Sixth, consistent with DLP’s April 25 commentary, the references to “generalized” in §1.3.1 merit deletion. References to “generalized limitation in intellectual functioning” are anachronisms. They were present in the 1983 AAMR definition. See AAMR, Mental Retardation: Definitions, Classification, and Systems of Supports, 10th Edition (2002), at p. 22. The 2002 AAMR criteria affirmatively reject the notion that limitations must be “generalized”. Rather, they recite that “within an individual, limitations often coexist with strengths”. At pp. 8 and 23.

Seventh, in response to DLP’s inquiry concerning the qualifications of some higher functioning individuals (e.g. those with Prader Willi or Asperger’s), DDDS indicated that they would still have to be deficient in one adaptive skill context under §1.4.1.1. Consistent with the April 25

commentary, SCPD recommends that DDDS consider a similar approach to I.Q. in assessing mental retardation. Rather than invariably using full-scale I.Q., SCPD recommends that DDDS determine eligibility under the mental retardation category based on a qualifying score on a major scale. For example, on the WAIS and WISC-III, a verbal, performance or full-scale I.Q. score could be used. Consistent with the attachment, the WISC-IV contains 4 major scales - verbal comprehension index, perceptual reasoning index, working memory index, and processing speed index. Consistent with the attachments, the Social Security Administration approves applicants under the listing for mental retardation based on meeting any major “scale” (e.g. FS; V; P). This approach is also consistent with the AAMR view that “within an individual, limitations often coexist with strengths”.

Eighth, §1.3 is problematic since it is more restrictive than the current (7/00) regulation. It categorically limits DDDS eligibility to the 4 listed conditions to the exclusion of all others. If a current client or applicant does not have a clinical diagnosis of Mental Retardation, Autism, Asperger’s, or Prader-Will Syndrome, they will be categorically ineligible for DDDS services. This is contrary to the Division’s enabling statute which contains no such limitation. See attached Title 29 Del.C. §7909A(b). Although the “Summary of Proposed Changes” section characterizes deletion of all references to “brain injury” and “other neurological conditions” as benign, this is inaccurate. Clinicians rarely include a diagnosis of mental retardation for patients with TBI, even moderate to severe TBI. Moreover, even using the most liberal interpretation of the DDDS regulation, all forms of pervasive developmental disorder (PDD) apart from Autism and Asperger’s will be subject to stricter eligibility standards. DDDS does not require significant limitation of intellectual functioning for Autism or Asperger’s, but it will be required for all other forms of PDD.

Parenthetically, DDDS justifies Section 1.3, in part, based on the Department of Education’s inclusion of Asperger’s within its definition of Autism. However, the Department’s regulation (attached) actually defines Autism as including both Asperger’s Syndrome and Pervasive Developmental Disorder (PDD). The DDDS proposed regulation anomalously excludes PDD or applies stricter eligibility standards to PDD.

SCPD has the following recommendations.

A. Reinstate a variation on the current reference to “brain injury”. As DDDS noted at the April 26 meeting, DDDS currently serves a number of individuals with brain injury. The current standard would encompass both TBI [Dementia Due to Head Trauma (294.1)] and ABI, including Vascular Dementia (290.4x). SCPD recommends adding the following §1.3.5: “Brain Injury, including Dementia Due to Head Trauma (294.1) (American Psychiatric Association Diagnostic & Statistical Manual - IV, 1994)”.

B. Reinstate a variation on the current reference to “neurological condition”. SCPD recommends adding the following §1.3.6: “A neurological condition closely related to those listed in Pars. (1) - (5) of this subsection; including pervasive developmental disorder (American Psychiatric Association, Diagnostic & Statistical Manual-IV, 1994); if such condition results in an impairment of intellectual functioning and/or adaptive behavior similar to such conditions.” Apart from Autism and Asperger’s Syndrome, the PDD category encompasses Rett’s Disorder (299.80), Childhood Disintegrative Disorder (299.10), and Pervasive Developmental Disorder NOS (299.80). There are also forms of dementia

[e.g. dementia due to other general medical conditions such as hydrocephalus (294.1)] that should logically be served by DDDS. SCPD understands there were many individuals with hydrocephalus in the Stockley Center in the 1970s. Finally, severe Fetal Alcohol Syndrome or Shaken Baby Syndrome can result in very low intellectual functioning and depressed adaptive skills. There will invariably be some less prevalent conditions which result in intellectual or adaptive skill limitations similar to Mental Retardation, Autism, Asperger's, and Prader-Willi Syndrome.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations on the proposed regulation.

cc: Ms. Marianne Smith
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Mr. Brian Hartman, Esq.
Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council

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